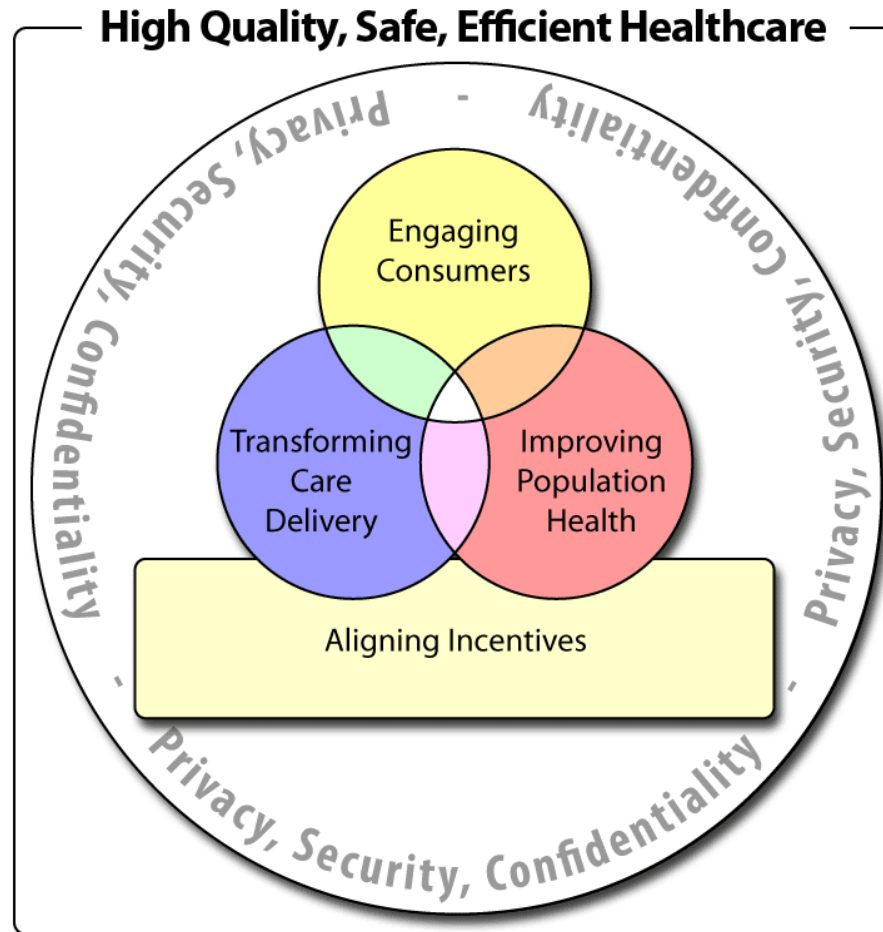




eHI Blueprint: Building Consensus for Common Action

Engaging Consumers

- **Shared Vision and Vision for Engaging Consumers**
- **Example Practices in Engaging Consumers**
- **Introduction to Engaging Consumers**
 - Principles for Engaging Consumers
 - Overview of Strategies & Actions
 - Areas without Consensus
 - Discussion/Questions and Answers
 - Co Chairs: Rachel Block, Project Director, Quality Strategies Initiative, United Hospital Fund and Len Lichtenfeld, MD, Deputy Chief Medical Officer, American Cancer Society
- **From Consensus to Common Action: What You Can Do**
 - Discussion
 - Co Chairs: Rachel Block, Project Director, Quality Strategies Initiative, United Hospital Fund and Len Lichtenfeld, MD, Deputy Chief Medical Officer, American Cancer Society
- **Wrap Up – Next Steps**
 - Co Chairs: Rachel Block, Project Director, Quality Strategies Initiative, United Hospital Fund and Len Lichtenfeld, MD, Deputy Chief Medical Officer, American Cancer Society



We envision a high-performing healthcare system, where all those engaged in the care of the patient are linked together in secure and interoperable environments, and where the decentralized flow of clinical health information directly enables the most comprehensive, patient-centered, safe, efficient, effective, timely and equitable delivery of care where and when it is needed most – at the point of care. [\[1\]](#)

In our vision, financial and other incentives are aligned to directly support and accelerate all of the key elements of transformation -- engaging consumers, transforming care delivery at the point of care, and improving population health -- in a secure, private, and trusted environment.

[\[1\]](#) *Institute of Medicine. Committee for Quality in Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press; 2001.*

Example Practices in Engaging Consumers

Vision for Engaging Consumers:

- Patients will be fully engaged in their own healthcare, supported by information and tools that enable informed consumer action and decision making, working hand-in-hand with healthcare providers. Tools that support consumer engagement are well designed and customized to the diversity of consumers. These tools are integrated into the delivery of care, and are conveniently available outside healthcare settings as well.

Principles:

- 1. Consumer Engagement in Healthcare:** Engaging consumers is critical in improving healthcare safety, equity, timeliness, quality, efficiency, and patient-centeredness. Health IT and health information exchange (HIE) should support informed consumer action and decision-making about health and healthcare, in partnership with providers; the absence serves as a barrier to achieving these goals. In addition, consumers need clear information, shaped by their input, about how to participate more fully in their own health and healthcare.
- 2. Consumer Access and Control of Personal Health Information:** Consumers have the right to access all of their own health information in an understandable form, as well as to annotate and request corrections to this information. Providers, payers and others who hold personal electronic health information have an obligation to make that information readily accessible or to facilitate its availability to the consumer. Individuals should be able to limit when and with whom their identifiably personal health information is shared.

Principles:

- 3. Consumer Access to Electronic Health Information Tools and Services:** Tools that engage consumers through the mobilization of electronic health information should be universally available to consumers regardless of whether or not they have health insurance, serve consumers' varied needs, be integrated in the delivery of care and conveniently available outside of care delivery settings. These tools should also be designed explicitly to meet the needs of diverse groups including the economically and geographically underserved, disabled, older, and culturally diverse populations.

- 4. Consumer Privacy:** Consumers have a right to privacy of their personal health information, consistent with all applicable federal, state and local law. (See also additional principles in Privacy, Security and Confidentiality.)

Principles:

- 5. Consumer Trust:** Consumers must be able to trust that their electronic health information is kept and used, with appropriate consent, in a secure, reliable and auditable manner. All stakeholders in healthcare who handle personal health information must make their policies regarding privacy and information use public, understandable and easily accessible.

- 6. Consumer Participation and Transparency:** All entities that govern, oversee, operate and/or create policy for the electronic exchange of health information should be transparent and open to meaningful consumer participation.

Consumer Engagement in Healthcare

1) Compile and analyze research, literature, and best practices relevant to successful consumer engagement in HIT/HIE.

Selected Action:

- 1.1 An existing, trusted Federal Agency and/or NGO should compile and analyze research, literature, and best practices relevant to successful consumer engagement in HIT/HIE. (2007-2008)

2) Lay out the value case for HIT and HIE (including benefits & risks) from consumers' perspective.

Selected Action:

- 2.1 Consumer Organizations, NGOs and Federal Agencies should lay out the value case (including benefits and risks), for HIT and HIE from the consumer perspective, with an emphasis on the potential impact on quality of care. Consumers should be included as an integral part of this process through an extensive community consultation technique. (2007-2008)

3) Develop an outreach and education plan for consumers and providers.

Selected Action:

- 3.1 A multi-stakeholder entity or forum (convened by an NGO) should develop an interactive outreach and education plan for consumers and providers that communicates the value case for HIT and HIE, how to evaluate and use particular tools and services, and how to participate more fully in one's own health and healthcare. Consumer Organizations, with foundation support, as well as Quality Organizations, and other stakeholders should assess, encourage, and validate efforts to implement these strategies for the benefit of consumers. A community consultation technique should be incorporated into the outreach process. Implementation must also take into account the diverse needs of consumer populations, including varying levels of health literacy. (2008)

4) Execute the outreach and education plans.

Selected Actions:

- 4.1 Consumer Organizations, and other stakeholders should execute an outreach and education plan for consumers. (2008-2009)
- 4.2 Provider Organizations should execute an outreach and education plan in partnership with the organizations leading the consumer outreach and education plan. (2008-2009)

5) Create consensus principles and standards that support consumer-control of electronic personal health information.

Selected Actions:

- 5.1 Consumer Organizations, Provider Organizations and NGOs should launch an open, transparent process involving every stakeholder of healthcare from both the public and private sectors to gain consensus acceptance around the following common principles and processes to support consumer control of electronic personal health information (2008-2009)
 - Consumers should have easy access to review, add notations and suggest corrections to existing information in their own records.
 - Consumers should be able to limit which of their health information could be shared with which providers, in a manner compliant with HIPAA, when applicable.
 - Consumers should be able to limit how their personally identifiable medical information is used outside of care delivery (e.g. for research), consistent with all applicable federal, state and local law.
 - Consumers should be able to easily designate others as proxies to act on their behalf (e.g. family member, caregiver, or guardian).
 - The process and infrastructure for monitoring and certifying compliance with the common principles above among organizations, initiatives and technologies.

6) Where electronically available, consumers should be able to acquire historical data from providers, payers and other entities to generate a more complete longitudinal record.

Selected Actions:

- 6.1 Federal Agencies, Purchasers and Health Plans should align incentives to support HIT adoption by providers. (2008-ongoing) (See also Aligning Incentives)
- 6.2 Congress should require digitization of an agreed upon core set of health data (such as the CCD or CCR) beginning in 2017.

7) Make a variety of types of useful tools and services available to consumers.

Selected Actions:

- 7.1 Federal Agencies, NGOs, Provider Organizations and other stakeholders (including the public and private sectors) should continue to develop free health content in digital form about a variety of conditions and in a variety of formats. (2007 - ongoing)
- 7.2 Congress should provide explicit long-term funding support to Federal Agencies such as the National Library of Medicine and the National Institutes of Health to develop free health content in digital form about a variety of conditions and in a variety of formats. (2007-ongoing)

8) Design content, tools, and interfaces to support different consumer needs, including but not limited to different languages, levels of health literacy, cultural perspectives, geographic access needs, and physical disabilities.

Selected Actions:

- 8.1 HIT Vendors should use focus group input and product testing that addresses consumer preferences in product development, taking into account the wide variety of consumer needs. (2007 - ongoing)
- 8.2 Provider Organizations and Researchers, with support from NGOs (foundations), should develop prototypes of useful electronic health information tools, with an emphasis on those that help consumers and providers to make decisions based on scientific evidence. Information from these efforts should feed into the development of guidelines described in 9.1. (2007 - ongoing)

9) Develop tools that explicitly help people to make evidence based decisions about their health.

Selected Action:

- 9.1 NGOs, in coordination with Federal Agencies (AHRQ) should study and develop guidelines and best practices for involving consumers in decision-making based on scientific evidence (e.g. information prescriptions, patient decision aids, and reminders/action items). These guidelines should be incorporated into the product certification process (See 5.4) (2007 - ongoing)

Consumer Trust

10) Develop, post, and adhere to Notices of Information Policies that explain how health information is handled.

Selected Actions:

- 10.1 NGOs should analyze how HIPAA applies to HIT/HIE and recommend how gaps in coverage need to be addressed. (2007-2008)
- 10.2 Given the lack of a comprehensive privacy-protective policy framework, any entity that may have contact with electronic personal health information (State and Community HIE Collaboratives, Health IT Vendors, Health Plans, Payers, Providers, etc.) should develop and publicly post a Notice of Information Policies. (2007-ongoing)

11) Establish accreditation processes for HIE networks and services and certification of HIT tools.

Selected Actions:

- 11.1 An NGO and/or Federal Agency should work with accreditation organizations to develop “policy standards” for State and Community HIE Collaboratives that establish compliance with the consumer principles described in 5.1. These “policy standards” should address attributes and/or procedures (for example, whether an HIE conducts its business in a transparent way). (2008-ongoing)
- 11.2. An NGO and/or Federal Agency puts into place a process to establish compliance by HIEs and others providing related services with the consumer principles described in 5.1. (2008-ongoing)

Consumer Participation and Transparency

12) Define organizational requirements for consumer participation and transparency and require compliance with those requirements.

Selected Action:

- 12.1 An existing, trusted entity (NGO, Consumer Organization or Federal Agency) should define and catalog the types of entities that govern, oversee, operate and/or create policy for the electronic exchange of health information and produce recommendations regarding the appropriate level of consumer participation and requirements for transparency that should apply to them. (2007-2008)

13) Strengthen and expand the cadre of consumer organizations well-versed in HIT/HIE policy issues at the national, state, and local level.

Selected Actions:

- 13.1 A trusted, existing NGO takes the lead in organizing/supporting development of a larger cadre of consumer organizations well-versed in HIT/HIE policy and coordinates their activities for maximum impact. (2007 on)
- 13.2: State and Community HIE Collaboratives and NGOs (foundations) should pay for individual consumers to attend HIT conferences in the states and at the national level, in order to support their education and participation in HIT and HIE initiatives. (2007-ongoing)

- **Consumers should be able to limit which of their health information could be shared with which providers...**
 - Concerns about impact on patient care
- **Consumers should be able to limit how their personally identifiable medical information is used outside of care delivery (e.g. for research), consistent with all applicable federal, state and local law.**

- **First Impressions?**
- **Feedback and Overall Reaction to the Engaging Consumers Section**
 - Principles
 - Strategies
 - Actions
- **What do you think will work? What won't?**
- **Any gaps or non-starters?**
- **Reaction to the issues without consensus?**

- **How can you help turn consensus into common action?**
- **Phase II: The Blueprint is designed so that stakeholders can build elements into their work plans and agendas in the coming years**
 - This process will tell us what is actionable
 - The Blueprint is a living document – as you consider incorporating elements, please provide feedback to eHI